

Governor's Organ Donation Advisory Committee

2005 Annual Report



LETTERS from the **Organ Donation Advisory Committee CHAIR**

and the Department of Health and Senior Services DIRECTOR



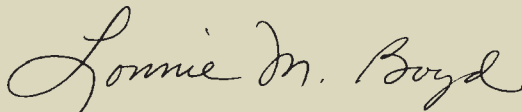
Dear Fellow Missourians . . .

It is an honor that I present to you, on behalf of the Governor's Organ Donation Advisory Committee, the 2005 Annual Report. Since 1996, the Missouri Department of Health and Senior Services and the Department of Revenue have worked diligently to develop, maintain, and enhance the Missouri Organ Donor Registry. I am pleased to highlight in this

report two new enhancements to the confidential registry. The first is an on-line enrollment feature and the second is called the STATLINE. The registry is, and remains, a vital tool for the organ and tissue donation community.

Registry enrollment entails a level of awareness and education related to donation that will continue to be a focus for the program in 2006. Together, the Governor's Organ Donation Advisory Committee, the Department of Revenue, the Department of Health and Senior Services, and procurement agencies will continue to develop the registry and increase donation awareness. I would like to take this opportunity to thank each and every individual, organization, and association that supports, and is committed to, saving and improving lives of our fellow Missourians through organ and tissue donation.

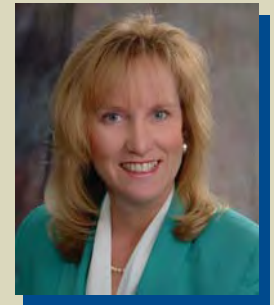
With greatest respect,



Lonnie M. Boyd, RN, BA, MS,
Chair, Missouri Governor's Organ Donation Advisory Committee

Dear Fellow Missourians . . .

The Missouri Organ Donor Program has continued to grow since its establishment in 1996. On behalf of the Missouri Department of Health and Senior Services, I am pleased to receive and extend to you the 2005 Annual Report of the Organ Donation Advisory Committee. The report highlights accomplishments that occurred this past year.



Of greatest importance is the growth of the registry that now has over two million participants; this is more than one-third of the state's population. You will also find in this report the heart-felt story of a young lady who, at 23 years of age, found herself on "the brink of death," in need of a heart transplant and a family who selflessly donated their daughter's organs. This story demonstrates the power the registry can have to, in the recipient's own words, "provide the gift of peace to your family and perhaps the gift of life to someone who is clinging to the hope they will have their own life adventures."

I commend the Governor's Organ Donation Advisory Committee members for their efforts in promoting the gift of life. Thank you for your continued support of the Organ Donor Program.

Sincerely,



Julia M. Eckstein, Director
Department of Health and Senior Services

Cover: Dr. Lisa Britt, heart recipient, with son, Benjamin, and daughter, Jennifer. Jennifer was named after Lisa's organ donor. (Story on Page 3.)

This publication was made possible by Missourians who provide voluntary contributions to the Missouri's Organ Donor Fund.

Alternate forms of this publication for persons with disabilities may be obtained by contacting the Missouri Department of Health and Senior Services at 888-497-4564. Hearing and speech impaired citizens telephone 800-735-2966. VOICE 800-735-2466. AN EQUAL OPPORTUNITY/AFFIRMATIVE ACTION EMPLOYER Services provided on a nondiscriminatory basis.

Missouri ORGAN DONOR PROGRAM Summary

The Organ Donor Program is implemented through the Department of Health and Senior Services, and guided by the Governor's Organ Donation Advisory Committee. The program had a successful 2005. A primary focus was, and is, to maintain and enhance the confidential organ donor registry. During 2005, program staff was able to add an on-line registration element. While enrollments through this feature aren't as high as expected, it is in its infancy, and on-line enrollments are expected to gradually increase over the next several years. Enrollment history and STATLINE are two additional enhancements that are featured in this report on Page 4.

Another focus of the program is to increase registry enrollment. Currently, over two million Missourians, of all ages, are registered as potential donors. For the second year in a row, the 18 to 24 year-old age group has seen the highest enrollment rate. Remarkably, 15 counties have 80% participation or higher for this age group, and it's worth noting that Warren, Holt, St. Charles, and Lincoln counties report over 90% participation in the same age group.

The Organ Donor Program is supported exclusively by voluntary contributions at the driver's license offices in the state and through direct contributions. Contributions to the Organ Donor Fund are preserved by statute and cannot be used as general revenue. Likewise, the Organ Donor Program is prohibited from receiving any general revenue funds. Fund balance as of January 31, 2006, is \$444,960.16 with \$274,460.99 spent in fiscal year 2005 (July 1, 2004 through June 30, 2005).

Staff looks forward to 2006 as they meet new challenges; privatization of branch offices to fee offices; fee office staff training; registry enhancements; and funding. As we look to the future, continuing to partner to save and improve the lives of our fellow Missourians through organ and tissue donation will remain our primary goal.

2005 GOVERNOR'S ORGAN DONATION ADVISORY COMMITTEE (GODAC)

Missouri Procurement Agency Representatives

Lonnie Boyd, Committee Chair
Ronald Walkenbach, Committee Vice-Chair and Cornea Recipient
Jan Finn

Hospitals Representative

Dr. Michael Perry, Kidney Recipient

Department Liaison

Lori Darr, Program Manager

Donor or Recipient Family Representatives

Lori Clark, Donor Mother
Lisa Atkins, Living Kidney Donor
Lucy Reinhart, Donor Mother
Dr. Lisa Britt, Heart Recipient

Ad Hoc Members

Elisabeth Sanders, Department of Revenue

Organ Program Statutes

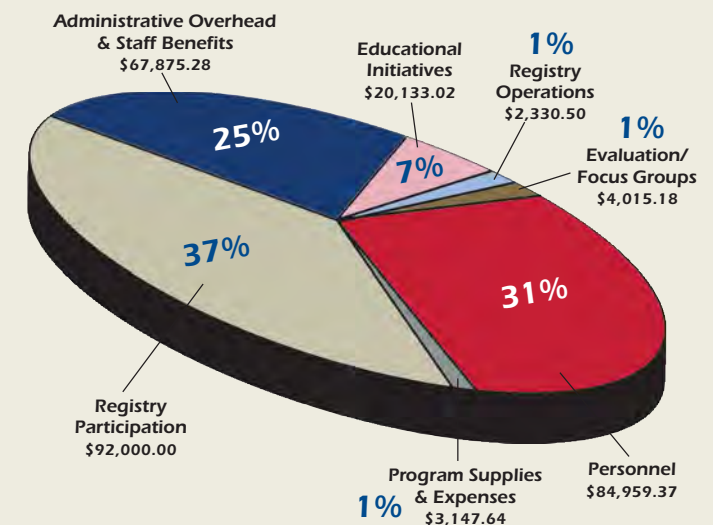
- RSMo 194.297 to 194.304 – Creation of the Organ Donor Program and Advisory Committee
- RSMo 194.210 to 194.290 – Uniform Anatomical Gift Act
- RSMo 301.171 & 301.181 – Driver's Licensing and Organ Donor Registry Fund
- RSMo 301.020 – Motor Vehicle Registration and Organ Donor Registry Fund
- RSMo 301.3125 – Organ Donor Special License Plate

2005 Organ Donor Program EXPENDITURES

The Organ Donor Program, exclusively supported by voluntary contributions, maintains the Organ Donor Registry and supports educational initiatives to increase donation awareness. The fund in which donations are deposited is protected by state statute and cannot be used to fund other programs or activities. Likewise, the Organ Donor Program is prohibited from receiving any state funding.

Income for fiscal year 2005, July 1, 2004 to June 30, 2005, was \$127,416.43; this includes \$1,420.97 from the state employee charitable campaign and \$1,867 from direct contributions to the Department of Health and Senior Services. Most voluntary donations are made at the driver's license office with an average of 5% of license applicants contributing \$1, a decrease from fiscal year 2004 of 8.4%. The percent of individuals supporting the fund continues to decline. The primary reason for the decline is the increase in driver's fees to an even \$20. Another contributing factor includes the addition of other options for voluntary contributions.

In fiscal year 2005, the Department of Health and Senior Services had authority to spend \$359,282 (appropriation). Expenditures for the year totaled \$274,460.99 and the distribution is illustrated in the pie chart on the right. Expenditures reflect a 13.2% decrease in total expenditures over fiscal year 2004 (\$316,200.82).



Life through Miracles

It is hard to believe that 15 years ago I was a second year veterinary school student struggling to keep up with class work. I was always exhausted and felt like I had the flu. A favorite uncle had unexpectedly passed away, as well as, one of my aunts. I blamed a lot of my lethargy on grief and the late night struggles to catch up on schoolwork.

By the time final exams took place in the spring, I was doing poorly in multiple classes. I was tired and out of breath as I slowly made my way to the school library to study. I never made it to the first exam. Instead I ended up in a trauma center with severe heart failure. I had an enlarged heart that was no longer able to function well enough to circulate my blood adequately. It is shocking to realize that at 23 years old you are on the brink of death and your life is about to irrevocably change.

My only option for survival was to undergo a heart transplant. Instead of taking final exams, I began a five month wait in the hospital praying to survive. On September 22, 1991, my heart transplant occurred just as my other organs were beginning to fail. My donor, Jennifer Renee Davis, was a happy teenager with a special boyfriend and had a car she earned the money to buy. She also loved animals and was a jogger.

Since that day my life has been an unusual adventure full of hurdles most people do not have to face. At the same

time, my triumphs have been more special simply by my survival. I went on to finish veterinary school, as well as, complete a large animal medicine internship in Canada. My next step was to move to Washington State University. There I obtained a master's degree in veterinary science, completed a radiology residency, and met John, the man brave enough to take on my history and become my husband.

The road I am traveling has not always been smooth, and there have been times it seemed certain that my adventures would be cut short. I have been through countless episodes of rejection, some of them fairly severe and of long duration.

The most frightening battle I have fought, and thankfully won for now, is with cancer. In 2000 I was diagnosed with lymphoma after rupturing my small intestine. The odds of me surviving this type of cancer given its location were very low.

With the loving support of my husband, family and friends, I endured six rounds of chemotherapy and went into remission. Thankfully, I have remained in remission and my long-term prognosis is now good.

One of the saddest sacrifices I have made during my cancer treatment was my fertility. The chemotherapeutic drugs induced menopause and I was told I would not be able to have children. As I have wanted children all my life, this was hard news to take. At the same time, we knew there are many thousands of children who needed



(Above left) Jennifer Davis, Lisa's heart donor. (Right) Jennifer Davis' family on Lisa and John's wedding day. (l-r) Jamie, Debbie, John, Lisa, Rosita and Jonathon.

adoption, and I was grateful to still be alive. Fortunately, predictions that I would not come out of menopause were incorrect and we began fertility treatment to try to have a child in 2002.

Imagine our delight when we found out I was pregnant in late 2003. We were very excited although a bit nervous given that it is still fairly uncommon for heart recipients to have children, especially when their transplant is 12 years out! After a few bumps during my pregnancy, our son, Benjamin was born on May 11, 2004. Words will never describe how happy we were and how much fuller our lives felt. We were so grateful for this much-wanted child. Our lives changed once again as we entered into my favorite adventure thus far— parenthood!

We decided we wanted Benjamin to have the gift of a sibling and went back to see the fertility specialist only to find out I was already pregnant! On November 2, 2005, Benjamin's baby sister, Jennifer, was born. Now our lives were complete. I had my precious son named after my father, and a 14-year-old dream come true with the birth of my daughter, who I had always wanted to name after my organ donor.



(Clockwise) Lisa before her heart transplant. Lisa during her large animal medicine internship, after her heart transplant; and Lisa at her graduation.

The Missouri Organ Donor Registry

is **Voluntary and Confidential**

You do not have to belong to the registry to be an organ donor. Talking with your family is the best way to express your choice to be a donor. Joining the registry will also help by putting your wishes in writing. For more information or to join the registry, please call 888-497-4564 or visit us online at www.dhss.mo.gov/organdonor.



My life is just one of many that was saved by organ donation. Without the gift of life from my organ donor through her mother's consent, I would not be here today. I would not have had the incredible journey I embarked on in 1991— no veterinary degree; no teaching veterinary radiology to students at the University of Missouri College of Veterinary Medicine. I would not have met my wonderful husband nor born my precious children.

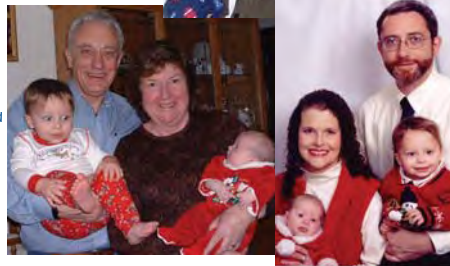
Our children are the only grandchildren for both of our parents. To see them with their grandparents is a joy. Two aunts and one uncle also love my children. It seems like a just reward for my mother for all the worrying and praying she has done throughout the years.

So many people's lives would have been negatively affected if my donor's mother had not selflessly given her daughter's organs for transplantation. Her gift allowed me to become a mother myself and words cannot express my gratitude. You have only to look at my beautiful, healthy children to see what a phenomenal thing organ donation is.

Yet the decision to donate is a personal one and sometimes difficult for our loved ones to make if they do not know our wishes. That is why the organ donor registry is such a powerful tool and a blessing to family members. It lets them know your wishes to help others through organ and tissue donation.

Sign up today at www.missouriorgandonor.com to give the gift of peace to your family, and perhaps the gift of life to someone who is clinging to the hope they will have their own life adventures.

(Above right) Lisa's mother, Elaine, and stepfather, Brent, holding Benjamin and Jennifer. (Far right) Lisa, John, Benjamin and Jennifer. (Right) Lisa's parents-in-law, Rose and David, also with Benjamin and Jennifer.



Registry **ENHANCEMENTS**

There are several enhancements that have been made to the registry: on-line enrollment, enrollment history and STATLINE. Each of these features is highlighted in the following paragraphs. If you would like more details, please contact the Missouri Organ Donor Program at 888-497-4564.

On-line enrollment was designed to give individuals a quick, easy, secure, and confidential method to enroll as an organ donor. The on-line process has helped with initial data entry time, but record verification time has remained the same. To enroll on-line visit: www.missouriorgandonor.com.

Enrollment history is now available. Each time an individual registers to be an organ donor while visiting one of the state's license offices, submits a paper application, or registers on-line, the registry records the date. The enrollment history only shows the dates of when the registrant did an on-line, paper, or license office enrollment. It does not show location or other personal information. At the time of organ/tissue procurement, a transplant coordinator will pull information from the registry that now includes the date of enrollment history. Enrollment history illustrates to family members how important the issue of organ donation was to their family member.

A registry enhancement called **STATLINE** is named after the organization called Statline. This organization serves as a backup to Mid-America Transplant Services (MTS). Currently staff accesses the registry to assist with back up registry referrals. Statline developed the software program interface so that when an individual referral is typed in as a possible organ/tissue donor, the system works in the background of their existing system, connects to the Organ Donor Registry, searches the registry to determine if the possible donor is actually registered, and then if it locates information on the individual, pulls it up for them to print. This means that every referral using this system will provide more efficient lookups and ensures that every referral is looked up. The system has security measures in place to compensate for staff turnover. Statline and the Department of Health and Senior Services jointly own the software rights. The department developed the code and provides the web service and security protocol for STATLINE.

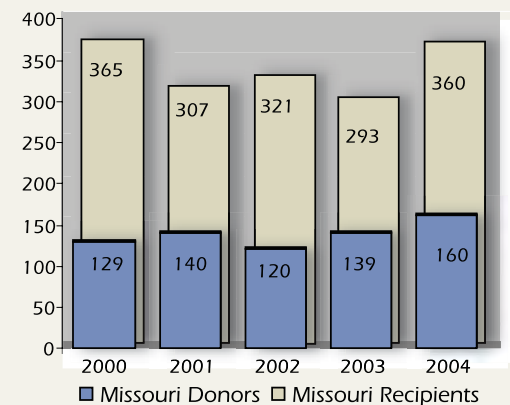
ORGAN DONATION and Transplantation in Missouri

The general health of the donor and the circumstances of their death influence the number of lives impacted by organ and tissue donation. One organ donor can save the lives of up to seven organ recipients and as many as 50 people can benefit from tissue gifts. Life-saving gifts through organ donation include the kidneys, liver, lungs, heart, pancreas and small intestines. Tissue transplants include heart valves, blood vessels, skin, bones, connective tissues, and the corneas of the eyes. **Even people with chronic health conditions, such as diabetes, high blood pressure and hepatitis, can provide life-saving gifts through organ and tissue transplantation.**

The graph illustrates the number of Missouri residents who donated organs after their death and the number of Missouri residents that received an organ transplant from a deceased donor. The average number of Missouri residents that have received a transplant from a living donor is 93.

To learn more about donation and transplantation statistics, visit the United Network for Organ Sharing website at www.unos.org.

United Network for Organ Sharing (UNOS)



Based on Organ Procurement Transplant Network (OPTN) data as of February 24, 2006. Data is subject to change due to future data submission or correction.

This work was supported in part by Health Resources and Services Administration contract 234-2005-370011C. The content is the responsibility of the authors alone and does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.*

Organ Donor

January 1, 2005 - December 31, 2005

REGISTRY Participation

ADAIR	Kirksville	37%	DEKALB	Maysville	32%	LINCOLN	Troy	39%	RIPLEY	Doniphan	9%	
ANDREW	Savannah	26%	DENT	Salem	21%		Elsberry	33%	SALIN	Marshall	30%	
ATCHISON	Rock Port	38%	DOUGLAS	Ava	20%	LINN	Brookfield	29%	SCHUYLER	Lancaster	36%	
AUDRAIN	Mexico	26%	DUNKLIN	Kennett	22%	LIVINGSTON	Chillicothe	23%	SCOTLAND	Memphis	23%	
	Vandalia	48%		Malden	21%	MACON	Macon	20%	SCOTT	Sikeston	18%	
BARRY	Cassville	32%	FRANKLIN	Pacific	46%	MADISON	Fredericktown	22%		Chaffee	20%	
	Monett	35%		St. Clair	29%	MARIES	Vienna	25%	SHANNON	Eminence	25%	
BARTON	Lamar	34%		Washington	47%	MARION	Hannibal	27%	SHELBY	Shelbina	31%	
BATES	Butler	33%		Union	42%		Palmyra	37%	ST CHARLES	St. Charles	30%	
BENTON	Warsaw	30%	GASCONADE	Sullivan	26%	MCDONALD	Pineville	27%		Wentzville	39%	
BOLLINGER	Marble Hill	22%		Hermann	38%	MERCER	Princeton	37%		Harvester	24%	
BOONE	Columbia	34%	GENTRY	Owensville	26%					O'Fallon	37%	
BUCHANAN	St. Joseph	33%		Stanberry	27%	MILLER	Eldon	26%	ST CLAIR	Osceola	28%	
BUTLER	Poplar Bluff	16%	GREENE						ST FRANCOIS	Bonne Terre	28%	
CALDWELL	Kingston	32%		Republic	32%	MISSISSIPPI	Charleston	23%		Farmington	26%	
CALLAWAY	Fulton	28%		Glenstone	42%	MONITEAU	California	32%	ST LOUIS	Afton	14%	
CAMDEN	Camdenton	33%	GRUNDY	South Fremont	35%	MONROE	Paris	14%		Florissant	22%	
CAPE GIRARDEAU	Cape Girardeau	27%		Springfield	36%		Monroe City	36%		AAA St. Louis	36%	
	Jackson	16%	HARRISON			MONTGOMERY	Montgomery City	38%		Ferguson	13%	
CARROLL	Carrollton	6%	HENRY	Trenton	29%	MORGAN	Versailles	31%		Chesterfield Contract	38%	
CARTER	Van Buren	23%	HICKORY	Bethany	19%	NEW MADRID				Overland	10%	
CASS	Harrisonville	29%		Clinton	27%		New Madrid	18%		North County	7%	
	Belton	25%	HOLT	Hermitage	39%	NEWTON	Neosho	24%		Creve Coeur	35%	
CEDAR	Stockton	27%	HOWARD	Mound City	26%	NODAWAY	Maryville	46%		Des Peres	42%	
CHARITON	Keytesville	30%	HOWELL	Fayette	32%					West County	28%	
CHRISTIAN	Ozark	36%		Willow Springs	34%	OREGON	Thayer	10%		South County	2%	
	Nixa	30%		West Plains	27%		Alton	25%		Bridgeton	30%	
CLARK	Kahoka	26%		Mountain View	28%	OSAGE	Linn	32%		Clayton	39%	
CLAY	Liberty	36%	IRON							Oakville	15%	
	Gladstone	29%		Ironton	19%	OZARK	Gainesville	29%	ST LOUIS CITY	St. Louis City Hall	25%	
	North Kansas	11%		Viburnum	28%	PEMISCOT	Caruthersville	14%		South Kingshighway Contract	20%	
	Excelsior Springs	28%	JACKSON			PERRY	Perryville	31%		Northside	10%	
CLINTON	Plattsburg	28%		Lee's Summit	90%	PETTIS	Sedalia	27%	STE GENEVIEVE	Ste. Genevieve	29%	
	Cameron	20%		Grandview	32%	PIELPS	Rolla	42%	STODDARD	Dexter	20%	
COLE	Jefferson City	36%		Blue Springs	17%	PIKE	Bowling Green	29%	STONE	Crane	30%	
	Jefferson City Mini Branch	38%		AAA Kansas City	48%		Louisiana	10%		Lakeview/Branson West	34%	
	Jefferson City Mail In	40%		Sugar Creek	23%	PULASKI	Waynesville	32%	SULLIVAN	Milan	16%	
COOPER	Boonville	29%		Independence	18%	PUTNAM	Unionville	23%	TANEY	Branson	45%	
CRAWFORD	Steelville	27%		Kansas City	21%					Forsyth	26%	
	Cuba	28%		Raytown	25%	RALLS	New London	20%	TEXAS	Licking	13%	
DADE	Greenfield	38%	JASPER							Houston	23%	
DALLAS	Buffalo	24%		Sarcozie	27%	PLATTE	Platte City	43%		Cabool	31%	
DAVIESS	Gallatin	24%		Carthage	29%		Parkville	36%	VERNON	Nevada	31%	
				Joplin	29%	POK	Bolivar	30%	WARREN	Warrenton	25%	
			JEFFERSON						WASHINGTON	Potosi	22%	
				Twin City	36%	PHELPS	Rolla	42%	WAYNE	Greenville	17%	
				High Ridge	34%				WEBSTER	Marshfield	23%	
				Desoto	31%	PIELPS	Rolla	42%	WORTH	Grant City	25%	
				Arnold	30%	PIKE	Bowling Green	29%	WRIGHT	Mountain Grove	21%	
			JOHNSON				Louisiana	10%		Hartville	25%	
				Warrensburg	14%	PLATTE	Platte City	43%				
			KNOX									
				Edina	20%	PULASKI	Waynesville	32%				
			LACLEDE									
				Lebanon	32%	PUTNAM	Unionville	23%				
			LAFAYETTE									
				Lexington	37%	RALLS	New London	20%				
			LAWRENCE			RANDOLPH	Moberly	27%				
				Aurora	24%							
				Mount Vernon	34%	RAY	Richmond	28%				
			LEWIS			REYNOLDS	Ellington License Office	25%				
				Monticello	34%							

Registry GROWTH CONTINUES

Percentage of Adults Enrolled in the MISSOURI ORGAN DONOR REGISTRY by County

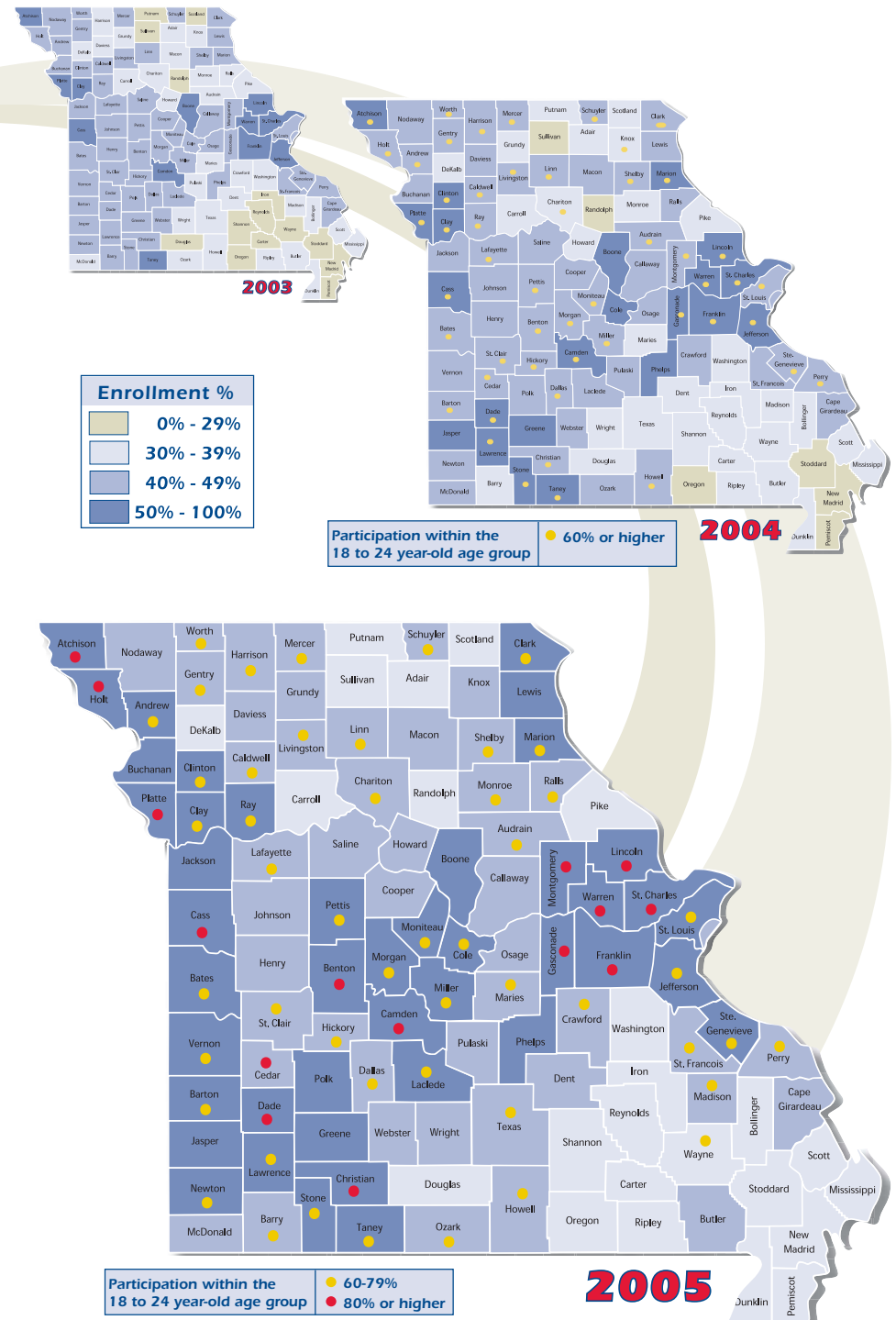


The Missouri Organ Donor registry participation data is analyzed by program staff and is used as a tool to evaluate education and awareness activities. This information allows staff to target specific areas and assist local partners with efforts to increase registry awareness. Using the 2000 Census data for Missouri, the maps illustrate the increase in average county enrollment since 2003. An average of 52% of Missouri residents ages 18 to 64 years of age are enrolled statewide. For all age groups, an average of 37% of Missourians are enrolled. Average registry enrollment has increased by 3% over the past year, from 34% in 2004 to 37% in 2005.

The age range of 18 to 64 is used as a primary indicator of registry demographics, since the majority of adults in this age range are licensed drivers and is given the opportunity to participate in the registry when obtaining a license or identification card. On average, 9,000 people enroll in the registry each week while visiting a license office.

Over two million Missourians, of all ages, are currently listed in the confidential registry of potential donors. The most dramatic increases in registry enrollment are seen within the 18 to 24 year-old age group. In 2005, 65 of the 114 counties averaged 60% or higher participation; in 2004, 51 counties; and in 2003, only 40 counties within this age group (shown on the 2004 and 2005 maps on right) averaged 60% or higher participation. The statewide average participation for the 18 to 24 year-old age group is now 58%, an increase of 3% since 2004 of 55%. Fifteen counties have 80% participation or higher for this age group, with Warren, Holt, St. Charles, and Lincoln with over 90% participation.

In addition to registering at any license office in the state, on-line enrollment is available to make enrollment easier and faster for Missourians. Anyone wishing to register can visit www.missouriorgandonor.com. A third option is to print off the enrollment form, complete it, and then submit it to the Department of Health and Senior Services directly. Individuals who enroll using the on-line service and direct enrollment methods receive a confirmation letter in return. In 2005, direct registry enrollments and modifications totaled 6,172, and there were approximately 117 new on-line enrollments. To learn more about the registry, please call 888-497-4564 or visit the program website at www.dhss.mo.gov/organdonor.





Organ Donor Program

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(573) 522-2847 or toll-free (888) 497-4564

www.dhss.mo.gov/organdonor